VIII: RACIAL AND ETHNIC MINORITIES

AREA OF EMPHASIS:

Racial and Ethnic Minorities

SCIENTIFIC ISSUES

Despite being 20-plus years into the HIV epidemic, HIV infection among racial and ethnic minorities continues to be a formidable health challenge, with little sign of abating. The disproportionate impact of HIV infection and transmission among this population has altered the social construction of these communities, affected their oldest institutions, and destroyed families across several generations, making it one more among many existing health disparities. Despite the increased number of agents in the therapeutic armamentarium, the introduction of a new class of agents, and a novel class of agents under investigation, urban centers continue to reflect HIV transmission rates that rival resource-poor settings internationally.

The reasons for this disproportionate impact, as well as the high rates of transmission, are complex and represent a confluence of social, economic, and historical factors. Social apathy, poverty, racism, homophobia, unequal access to health care resources, disproportionate impact of substance and alcohol abuse, marginalization of subpopulations within these communities (e.g., gay, bisexual, and transgendered persons), and the health impact of comorbid conditions that disproportionately affect this population (e.g., sexually transmitted infections [STIs] and hepatitis) underscore that a range of interventions will be necessary. Exploring each of these factors will be time-consuming and labor-intensive. However, the current HIV transmission rates mandate a more extensive and intensive effort in all areas.

Social, economic, and historical factors are complexly interwoven; whether the legacy of slavery, internment camps, or reservations, racial and ethnic minorities in the United States experience a disproportionate amount of poverty, as well as the associated social ills. HIV infection (as well as HIV-hepatitis C [HIV-HCV] coinfection) is at the intersection of these factors, given that substance abuse, survival sex, and commercial sex are associated with blood-borne pathogens and STIs.

Unequal access to health care resources continues to drive the epidemic as well as limit the potential for decreased transmission. Unequal access to health care means that fewer racial and ethnic minorities receive treatment, and as such may continue to facilitate HIV transmission. Limited health care access also means less exposure to health education messages, including prevention. Finally, limited access to health care means perpetuating the inadequate enrollment of racial and ethnic minorities within NIH-sponsored HIV clinical trials. As the epidemic reaches further into racial and ethnic minority communities, this failure leaves important questions about the impact of race and ethnicity upon treatment, treatment adherence, prevention, and disease progression.

PRIORITY FOR FUTURE RESEARCH:

- **Enhance the capacity of minority investigators, minority institutions, and minority community-based organizations to conduct multidisciplinary HIV research.**

Minority investigators remain significantly underrepresented among HIV investigators despite the demographics of the epidemic. Despite a sprinkling of minority investigator development programs across the NIH and the country, the bulk of minority investigators are located at majority institutions and do not participate in these programs. Those located at minority-predominant and minority-serving institutions are often challenged by lack of mentoring, large teaching loads, administrative duties, or little protected time. Expanded funding for allocated research infrastructure development at these institutions would help provide the skeleton upon which a program of minority investigator development could be built. This would include, but not be limited to, the development of basic science capacity at minority institutions, with bench-to-bedside applications as part of the capacity development. Majority and minority institution research partnerships with equitable and equal distribution of resources across all participating entities would also assist with not only capacity building but also minority investigator development. These partnerships would contribute to the bidirectional exchange of information important

to inform the research agenda in racial and ethnic minority communities and become part of the development of a self-sustaining, comprehensive HIV/AIDS research agenda at minority institutions. However, minority investigators are only part of a multidisciplinary effort; minority community-based organizations (CBOs) and minority institutions are an essential component. Minority CBOs include minority-predominant and minority-serving institutions. The involvement of minority communities is completed when minority institutions can develop academic-community partnerships in minority communities, addressing research questions that are of importance and interest to all participating entities.

There are inherent limitations and difficulties with this approach without a sustained and ongoing effort. Successful mentorship of a racial and/or ethnic minority investigator cannot be done without a commitment to sustained funding not only for pilot projects, but also for recruiting and retaining senior investigators as mentors. Mentoring for racial and ethnic minority investigators is essential, and cannot be achieved successfully on a shoestring budget. Offering incentives for senior investigators not only to identify minority investigators with research potential, but also to mentor these investigators, will begin to address the challenge of mentoring without financial resources. These incentives are needed for both the extramural and the intramural programs.

Incentives at the institutional level for the development, recruitment, and retention of minority investigators will be a critical component of the approach. Minority-predominant and minority-serving institutions will need to evolve from a mandate of primarily teaching (based upon their history and the reason for their existence) to research as well as teaching. A number of grant mechanisms exist to facilitate the development of minority institutions; however, these need to be reviewed and tracked by their outcomes to determine those that are the most (and the least) effective.

The development of minority investigators also provides an opportunity to develop additional opportunities for routine exchanges between community providers and the research community. Community constituency groups and community advisory boards are just one aspect of the bidirectional exchange needed between minority communities and those who come into the community to conduct research. These bidirectional exchanges are not optional; they are essential to the development of research questions of mutual interest to the investigator and the communities within which such research is conducted. When such questions are jointly identified and of mutual interest, the issue of recruitment and retention of adequate numbers of racial and ethnic

minorities to explore specific findings unique to that subgroup will cease to be a challenge. When minority communities can perceive that the findings from a research agenda have particular relevance to them, their interest and participation will increase. Maintaining representation of racial and ethnic minorities in clinical trials in numbers that reflect the local or regional epidemiology will become a mission possible.

PRIORITY FOR FUTURE RESEARCH:

- **Identify biomedical, sociocultural, and structural determinants, pathways, and mechanisms that maintain or perpetuate health disparities.**

The history of the treatment of domestic racial and ethnic minority populations within the health care system, as well as health care delivery, is at best a checkered one. Whether Tuskegee and African Americans, or smallpox in the blankets of Native Americans, these experiences have left a legacy of distrust in racial and ethnic minority communities of many organizational systems providing health care, conveying health messages, or conducting research. This mistrust affects not only health-care-seeking behavior, but also treatment adherence, as well as incorporating/utilizing health promotion messages. While this remains a complex and multifaceted problem, it will be essential to tease apart the myriad of sources that contribute to these disparities and to identify ways to modify or eradicate them. Bias, prejudice, stereotyping, unequal access to care, and low levels of health literacy only compound these challenges. HIV infection adds a new level of disparity, given the routes of transmission, and the impact of cultural norms and stigma upon sexual and drug-using behaviors. Just as the Institute of Medicine report demonstrated structural determinants that globally influence racial and ethnic disparities in health, similar evaluations are necessary to further identify the impact of these structural determinants upon treatment outcomes in HIV infection. Despite the advent of antiretroviral therapy (ART), there remains a difference between the treatment outcomes (such as survival) in Caucasians and African Americans or Latinos.

Investigators, clinicians, policymakers, and communities will need to work together to identify, test, and implement novel strategies to identify and remedy the ongoing gap in health outcomes in HIV infection. In this area, community-based interventions and efforts will be essential, requiring academic-community partnerships. These partnerships will require an investment of resources that may be greater than those for university-based clinical trials, however; the investment from the community will be essential. In addition to health disparities, economic and educational disparities affect

racial and ethnic minorities. Continued research to explore the interactions between these disparities is needed for all racial and ethnic minorities, but especially those significantly underrepresented in clinical studies, including Native Americans, Alaska Natives, and individuals of mixed race.

PRIORITY FOR FUTURE RESEARCH:

- **Develop and test innovative models, research methods, and measures of risk behavior in racial and ethnic minority areas.**

Incorporation of racial and ethnic minorities in increased numbers in prevention interventions will also require a new and creative mode of thinking. Despite two decades of prevention research and intervention, significant segments of the minority community are either missing prevention messages, ignoring prevention messages, or failing to incorporate prevention messages into their lifestyles. In addition, a number of racial and ethnic minorities are underrepresented in these behavioral trials: Native Americans, Alaska Natives, and Asian Pacific Islanders. Despite the success of specific research instruments and methodologies in other population groups affected by the HIV epidemic, given the ongoing and increasing impact of the epidemic in minority communities, there is a powerful argument for the development of novel survey instruments and methodologies that are culturally and contextually appropriate. In order to develop, test, and evaluate such novel approaches, a more broad-based approach to HIV prevention in minority communities will be necessary.

Prevention, defined in its broadest terms, is an essential intervention in racial and ethnic minority communities. However, prevention interventions must be contextually and culturally appropriate, and address the risk behaviors associated with HIV transmission in ways that are accepted by the community. Given the cultural context around the development of sexual norms and gender roles, replication of prevention interventions that succeed with one population group without modification for racial and ethnic minority populations are destined to fail. In addition to current practice and state-of-the-science interventions, additional research is needed not only to expand the range of interventions but also to enhance their effectiveness. These new or expanded interventions must be developed in partnership with racial and ethnic minority communities.

The translation of prevention research findings into practice, especially in racial and ethnic minority communities, is long and arduous, particularly given the multiple factors listed above that affect these communities. The barriers to effective prevention in these communities include, but are not limited to: organizational infrastructure development, limited opportunities

for routine exchanges between prevention researchers and front-line community providers, different definitions of effective prevention interventions between researchers and front-line community service providers, a paucity of minority investigators, and prevention methods that have little to no cultural relevance to the target population.

Organizational infrastructure development is an overarching need in racial and ethnic minority communities. Lack of organizational development, as well as the pervasive lack of significant and consistent infrastructure, limit the ability of racial and ethnic minority organizations to develop and maintain effective partnerships with academic and research entities through which prevention interventions (from behavioral to therapeutic) are delivered. Moreover, without this infrastructure, there is no institutional memory for development and expansion of preliminary efforts to continue work that was initiated in these communities. This continued need to start from the beginning presents challenges and frustrations to both the academic and research communities, as well as the community organizations. Sustained and consistent long-term investment in the organizational infrastructure of minority community organizations is a key component of the continued development and application of appropriate prevention interventions in this population.

PRIORITY FOR FUTURE RESEARCH:

- **Further exploration of the natural history of HIV disease and its consequences for racial and ethnic minority communities.**

HIV infection among racial and ethnic minorities occurs against a backdrop of a number of other comorbid diseases, including but not limited to hypertension, diabetes, cardiovascular disease, STIs, the hepatitides, and tuberculosis. While the treatments for HIV infection continue to expand, there are still gaps in the scientific knowledge base in understanding the impact of race as well as gender upon cytokines, p-glycoproteins, HIV disease manifestations, and response to therapy. The race-related renal dysfunction associated with HIV infection is but one example of how the natural history of the disease may differ between racial and ethnic groups. The complex interplay between host genetics, HIV infection, and treatment upon the course of HIV disease progression is not completely elucidated. How treatment alters the natural history of HIV infection in racial and ethnic minority communities is still not well characterized. Current studies provide conflicting and sometimes confusing results regarding the impact of race upon treatment outcome, as well as treatment side effects, such as lipid changes, lipoatrophy/lipodystrophy, hepatic dysfunction, and lactic acidosis as a few examples.

PRIORITY FOR FUTURE RESEARCH:

- **Clinical research must include racial and ethnic minorities in numbers that reflect their representation in the HIV epidemic.**

Health disparities are only a part of the puzzle of HIV infection among racial and ethnic minorities. The effects of race upon p-glycoproteins, proteomics, genomics, and HIV treatment and drug resistance have yet to be fully defined. The mediating influence of hormones in conjunction with race remains to be explored. These questions will be easier to address when clinical trials are designed with sufficient power to detect racial, ethnic, and gender differences. In order to recruit as well as retain racial and ethnic minorities within clinical trials, efforts must be targeted to the communities affected and community input incorporated during study design and implementation. Without such community participation, the mistrust of the health establishment in general and research in particular will continue to undermine the efforts at inclusion. As with other multifaceted and complex challenges in racial and ethnic minority communities, the solutions will not be fast, easy, or quick. Investment for the long term by the development of minority investigators, minority institutions, and community infrastructure, in ways very similar to resource-poor settings internationally, is sorely needed to change the current underrepresentation in research trials.

Barriers to health care access continue to factor into recruitment and retention into clinical trials for racial and ethnic minorities. These barriers may be geographic (given the location of the high transmission rates in the Southeast as compared to where major HIV centers are located), institutional, and individual. By identifying these discrete areas, and developing and testing interventions, we can learn not only more about the epidemic in these communities, but also how to better reach out to them to make them fully included in HIV research and treatment.

However, for many within racial and ethnic minority communities the major challenge of the epidemic is not solely inclusion in clinical trials. Access to treatment and adherence to therapy remain major challenges. With the increased cost of therapies and the diminishing resources to cover them, treatment adherence is driven by a complex interplay of factors, including access to treatment, cost, coverage, substance abuse, depression, and perceptions of treatment. As studies repeatedly show the marked difference in performance of therapeutic agents in clinical trial settings compared to urban clinics, further research on the individual, societal, and community factors that promote adherence are needed. The role of the provider-patient relationship cannot be underestimated, and studies

of the aspects of that relationship that positively and negatively affect adherence are also needed. Little remains known about the impact of health beliefs upon the treatment acceptance and adherence in minority communities, as well as the effect of chronic and traumatic stress upon adherence and chronic nonadherence. Chronic ongoing violence and exposure to violence frequently and often from a young age are common in minority communities. The impact of this exposure upon disease perception, need for treatment, and ultimately fatalistic views of death and survival are vastly unexplored in this population.

SCIENTIFIC OBJECTIVES AND STRATEGIES

OBJECTIVE - A:

Enhance and expand the capacity for multidisciplinary NIH-funded HIV research by underrepresented minority investigators, institutions, and communities. Minority is defined as any racial and ethnic group other than Caucasian.

STRATEGIES:

For the investigator:

- Expand and strengthen existing programs designed to increase the awareness of underrepresented minority investigators of NIH funding mechanisms for HIV/AIDS research.
- Conduct a review to determine the number of minority scientists produced as a result of existing NIH programs (such as the K award, minority biomedical research supplement) to support the transition from trainee to independent investigator.
- Convene an outside expert review panel to review the NIH's success in recruiting, retaining, and developing minority intramural and extramural investigators, and to make recommendations to the Director of the NIH for program improvement.
- Provide incentives for senior investigators to identify, develop, and mentor minority investigators in HIV/AIDS research.
- Establish an ongoing scholarship fund to enable junior minority investigators to attend scientific meetings.
- Charge the Center for Scientific Review to provide a plan for increasing the number of racial and ethnic minorities on review panels.
- Provide incentives, through existing funding mechanisms, for the development, recruitment, and retention of minority investigators in intramural and extramural research.

For the institution:

- Expand funding allocated for research infrastructure development at minority institutions.

- Partner minority and majority institutions with shared research interests for research program and infrastructure developments through the use of funding incentives and grant mechanisms.
- Continue to increase the capacity of minority institutions to support HIV/AIDS research through specifically designated NIH-wide programs.
- Improve basic science capacity at minority-predominant and minority-serving institutions through mentored training awards, infrastructure development, and majority-minority institutional partnerships and collaborations.
- Facilitate the establishment of research partnerships between minority institutions and the communities they serve by enhancing and expanding initiatives that support research in minority communities.
- Expand training opportunities at minority institutions by enhancing existing mechanisms to provide personnel necessary for the successful conduct of HIV/AIDS research.
- Form a multiethnic, multiracial external advisory committee to assist in determining the unique needs of minority institutions, including tribal entities.
- Provide financial support through existing mechanisms to support strategic planning at minority-serving and minority-predominant institutions to develop an HIV/AIDS research agenda.

For the community:

- Increase minority representation on community advisory boards for HIV research to reflect their *current* incidence and trends in the epidemic.
- Enhance and expand technology transfer programs to expedite transfer of state-of-the-art information from the bench to the bedside and to the community.
- Disseminate effective prevention interventions to racial and ethnic minority communities through CBOs, providers of HIV-related care and services, and minority-predominant and minority-serving institutions.

- Facilitate the establishment of research partnerships between minority institutions and the communities they serve by enhancing and expanding initiatives that support research in minority communities.
- Establish mechanisms to include community consultations in NIH-funded extramural research from study development to the dissemination of study results.
- Expand information dissemination and regional technology transfer programs in regions with high rates of HIV transmission within racial and ethnic minority communities.
- Share study results with research participants promptly through existing information dissemination mechanisms as well as through community organizations.
- Fund community-driven participatory research, to facilitate transfer of community knowledge/observations to researchers and vice versa.
- Fund training of CBO staff as well as community participants about clinical trials and the clinical trial process to enhance both participation and retention of racial and ethnic minorities, especially in vaccine-related trials.
- Develop, test, and promote successful strategies linking community organizations with NIH research performance sites through the use of Internet resources, such as AIDSinfo.nih.gov.

OBJECTIVE - B:

Identify and examine the sociocultural and structural determinants, pathways, and mechanisms that enhance, sustain, or perpetuate health disparities.

STRATEGIES:

- Design clinical trials with sufficient power to detect racial, ethnic, and gender differences.
- Encourage basic research and its clinical application to elucidate the impact of culture-, race-, and gender-related influences upon the response to HIV infection and treatment.
- Design and conduct studies to determine the factors that promote and/or preclude early access to care and treatment.
- Examine the impact of traumatic stressors such as acculturative stress, discrimination, racism, and homophobia upon health outcomes.
- Explore the impact of economic and educational inequities among understudied populations such as Native Americans and mixed-race individuals and observed health disparities in HIV infection.
- Explore the impact of race/ethnicity, poverty, language, and lack of education upon the observed disparity in HIV infection among border communities, as well as among documented and undocumented immigrants.
- Study the impact of race/ethnicity and gender upon those cultural contexts and social norms that may influence HIV transmission as well as disease progression.
- Study the multiple factors that disproportionately impact racial and ethnic minorities (such as racism, poor education, poverty, homelessness) and their role in creating the observed health disparities at the individual and community levels.
- Promote and sustain interagency research to:
  - Determine the impact of criminal justice, economic, and educational disparities in the health outcomes of racial and ethnic minorities with HIV infection.

- Conduct research on the role of health care disparities and public policy factors in sustaining the disparities in the health outcomes of racial and ethnic minorities with HIV infection.

OBJECTIVE - C:

Conduct clinical research that includes numbers of racial and ethnic minorities that reflect the current incidence and epidemiological trends in the HIV/AIDS epidemic domestically.

STRATEGIES:

- Conduct research to examine the effects of HIV infection upon the physiologic, immunologic, hormonal, and neuropsychological development of racial and ethnic minority adolescents.
- Conduct appropriately powered clinical trials to explore differential responses to treatment, metabolic toxicities, and immune responses to HIV infection in racial and ethnic minorities.
- Maintain representation of racial and ethnic minorities in trials designed to prevent and reduce HIV transmission in numbers that reflect the local (or regional) epidemiology.
- Enhance collaboration across Institutes that jointly conduct clinical trials in racial and ethnic minorities to:
  - Promote consistent and timely sharing of trial data with these communities;
  - Expedite the production of reports, consensus conferences, or other materials emanating from these trials; and
  - Enhance opportunities for the translation of trial results to the actual needs of racial and ethnic minority communities.
- Develop, test, and support clinical research methodologies that examine prospectively racial/ethnic/gender/sexual orientation differences in transmission, pathophysiology, and treatment outcomes.
- Encourage academic-community partnerships to enhance clinical trial participation by racial and ethnic minorities.
- Continue to conduct trials on the impact of alcohol and drug use on the success of clinical interventions in racial and ethnic minorities, as well as disease progression and treatment.
- Promote awareness and understanding of the ethics of clinical research, as well as the protections required for research participants in racial and ethnic minority communities and the CBOs that serve them.

- Encourage the exploration of proteomics and genomics to determine the effects of race, gender, and age upon immune response to HIV infection.
- Continue the study of the biology of HIV infection among racial and ethnic minorities, including:
  - The effect of race/ethnicity and gender upon immune dysfunction and the development of opportunistic infection;
  - The effect of race/ethnicity and gender upon p-glycoproteins and their role in HIV drug resistance; and
  - The impact of preexisting health conditions that disproportionately affect racial and ethnic minorities, such as diabetes, hypertension, and cardiovascular disease, upon HIV infection.

OBJECTIVE - D:

Explore the natural history of HIV disease and its consequences in racial and ethnic minority communities.

STRATEGIES:

- Study the impact of other comorbid diseases including the hepatitides, tuberculosis, mental illness, diabetes, alcohol use and abuse, substance abuse, and STIs upon HIV-related morbidity, mortality, and disease progression in minority communities.
- Support research that explores factors that promote or prevent HIV transmission, including:
  - The role of extended and nuclear family and caregivers;
  - The role of traditional and nontraditional organizations upon social structure and norms;
  - The role of peer and social networks; and
  - The individual as well as community interface with institutionalized care delivery systems.
- Study the impact of alcohol and other substance abuse treatment as an approach to HIV prevention.
- Determine the impact of alcohol use and abuse, substance abuse, and mental health disorders upon HIV disease in racial and ethnic minority communities.
- Determine the impact of mental health and substance abuse disorders upon the comorbidities associated with HIV disease.
- Explore the intersection of poor health indicators, comorbid diseases, and HIV disease progression in racial and ethnic minorities, to identify multiple points for intervention.
- Determine the impact of race-related factors upon disease progression, if any, in understudied populations such as Native Americans, Alaska Natives, Pacific Islanders, and Native Hawaiians.
- Determine the impact of structural factors within health-related organizations, such as insurance status and institutional racism, upon when racial and ethnic minorities present for HIV-related care and its impact upon disease outcome in these populations.

- Identify the factors that influence HIV transmission among racial and ethnic minorities.
- Continue to expand research to identify specific mechanisms of transmission in racial and ethnic minorities:
  - Enhance and expand research on the potential impact of vaccines and microbicides upon HIV transmission among racial and ethnic minority communities.
  - Conduct research on the impact of rapid testing for HIV infection upon transmission.
  - Promote research to explore the impact of access to treatment and services in HIV transmission.
- Conduct research on HIV infection among older individuals and its impact upon HIV transmission in minority communities.

OBJECTIVE - E:

Develop and test innovative models, research methods, and measures of risk behavior in racial and ethnic minority communities.

STRATEGIES:

- Develop, pilot, test, and evaluate new measures of HIV risk behavior that are culturally and contextually appropriate for racial and ethnic minorities.
- Develop new models of HIV behavioral interventions that incorporate common stresses for racial and ethnic minorities, such as racism and poverty.
- Encourage the development of novel sampling methods to enhance the representation of racial and ethnic minorities in clinical trials, with attention to sampling adequately from national-origin subgroups.
- Identify resiliency and protective factors in racial and ethnic minority communities, and test them for impact upon decreasing HIV transmission.
- Study HIV risk behaviors of underrepresented racial and ethnic minorities, such as American Indians/Alaska Natives and Asian Pacific Islanders.
- Fund the development and testing of new sampling methodologies in racial and ethnic minority communities.
- Encourage the study of intergenerational trauma and its impact upon HIV risk behavior in racial and ethnic minority communities.
- Validate existing measures for translational, cultural, and linguistic equivalents for each of the communities in which they are to be used.

OBJECTIVE - F:

Study the impact of treatment and adherence upon the health outcomes of HIV infection in racial and ethnic minority communities.

STRATEGIES:

- Continue to study the short- and long-term effects of nonadherence in racial and ethnic minority communities.
- Determine the impact of short- and long-term nonadherence upon drug-resistant HIV infection, multidrug-resistant tuberculosis, and HIV disease progression.
- Conduct research into the role of racial, ethnic, sexual orientation, and gender differences upon adherence as well as nonadherence.
- Identify factors at the individual, societal, and community level that promote adherence.
- Study the impact of chronic and traumatic stress upon health outcomes, adherence, and nonadherence.
- Study the role of provider-patient interactions that negatively and positively affect adherence.
- Determine the impact of provider decisionmaking upon patient adherence.
- Conduct research on community-based multilevel interventions to promote adherence.
- Continue to study the role of complementary therapies upon treatment for HIV infection, its complications, and quality of life (such as symptom relief).
- Define the role and impact of health beliefs upon treatment acceptance and adherence in racial and ethnic minority communities.
- Continue to explore novel therapeutic regimens for HIV infection and associated coinfections.

FY 2006 OAR
Planning Group for
Racial and Ethnic Minorities

FY 2006 RACIAL AND ETHNIC MINORITIES PLANNING GROUP

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